

PERTH FORUM – CLAIMING FULL CITIZENSHIP 16th NOVEMBER 2015

Context for the Perth Forum – Claiming Full Citizenship

In October 2015, Vancouver hosted an international “Claiming Full Citizenship” Conference to which over 500 people came. The Conference was built on a belief that Individualised Funding by itself is not enough to ensure that people with disability have full citizenship rights. That alone doesn’t guarantee that they are treated as equal citizens. So the Conference examined how the notion of citizenship plays out for people with disability and what can be done to enhance people’s citizenship rights.

The notion of ‘citizenship’ is grounded in our understanding of Human Rights as stated in the Universal Declaration of Human Rights. Article 1 states: *All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.* Australia was one of the original signatories to this statement in 1948.

In Vancouver, Sue Swenson from the USA reminded us that the US Declaration of Independence is similarly grounded in fundamental human rights. It begins by saying: *We hold these truths to be self-evident, that all people are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness.*

The UN Convention on the Rights of Persons with Disability is an application of the Universal Declaration of Human Rights to people with disability and was adopted by the UN in 2006 and opened for signatures in March 2007. Australia was among more than 100 nations that signed the Convention on the Opening Day.

The United Nations website introduces the Convention with these words: *This Convention follows decades of work by the United Nations to change attitudes and approaches to persons with disabilities. It takes to a new height the movement from viewing persons with disabilities as "objects" of charity, medical treatment and social protection towards viewing persons with disabilities as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society.*

*The Convention is intended as a human rights instrument with an explicit, social development dimension. It adopts a broad categorization of persons with disabilities and reaffirms that **all persons with all types of disabilities must enjoy all human rights and fundamental freedoms.** It clarifies and qualifies how **all categories of rights apply to persons with disabilities** and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights; and areas where their rights have been violated, and where protection of rights must be reinforced.*

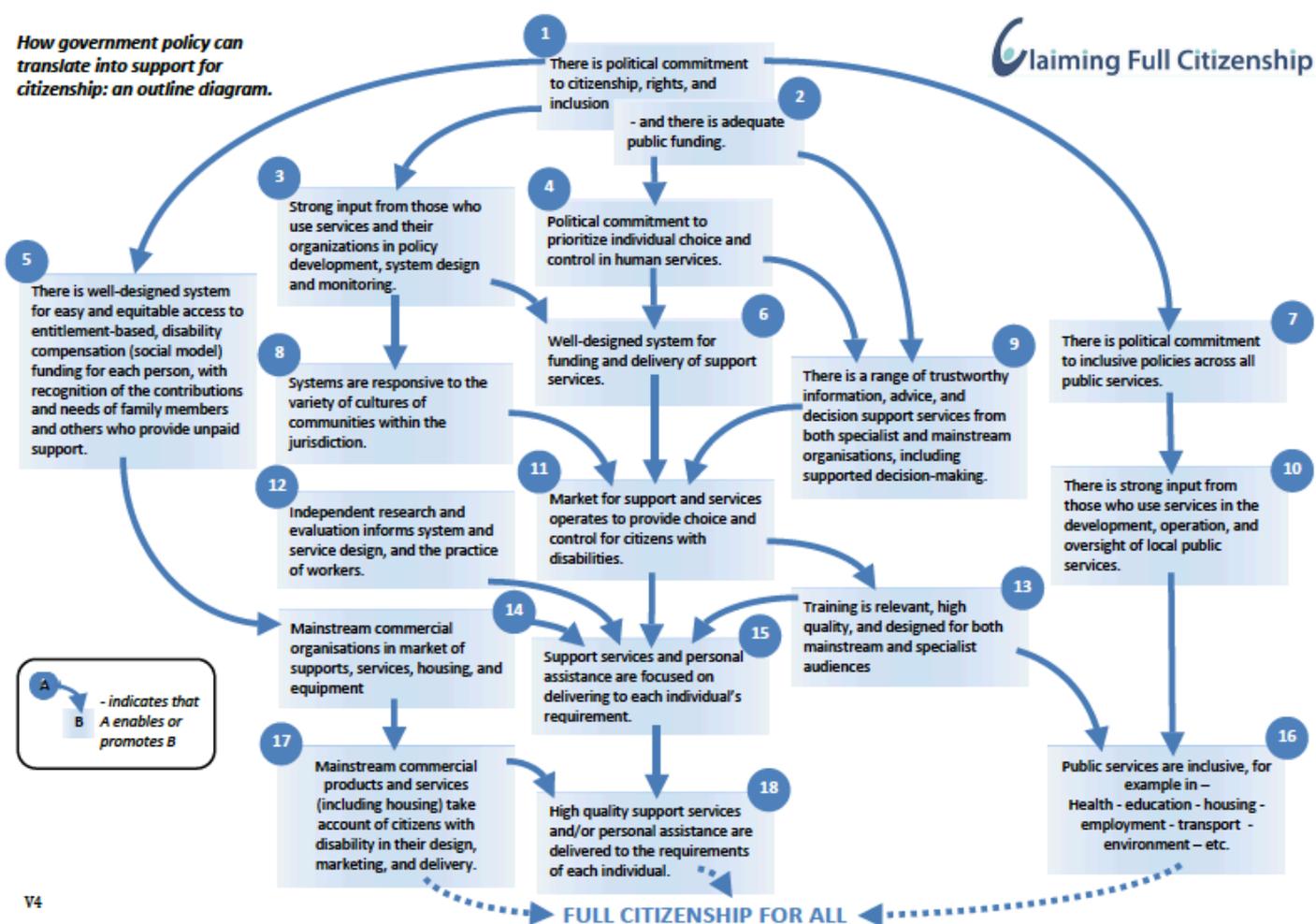
The Vancouver Conference that some of us attended last month was grounded in this ‘human rights’ understanding. It is important that we begin our deliberations today with a clear awareness of this rights basis. With the ongoing evolution of the NDIS reforms that affect models of service and support, it would be easy for us to focus on things like ‘what good service looks like’; or ‘how to manage risks and safeguards’ without considering how these things fit within Australia’s overt and legal commitment to upholding and enhancing the human rights of people with disability.

Developing the Vancouver Benchmarks

One aim of the Vancouver Conference was to produce a document that can be used by governments around the world to guide them in taking meaning action to promote and develop a society that fully includes people with disabilities as equal citizens. Engagement with this project has been slower than anticipated and it is still in development now. To ensure that it is a document that is broadly representative of people with disability and their family members, and that the voices and perspectives of people with disability are heard in the document, people who did not get to Vancouver are being invited to join the process (which is happening via a dedicated Facebook page: <https://www.facebook.com/groups/VancouverBenchmarks/>). Please follow this link and request to become a member of the group in order to join.

Steve Dowson (Chair of the VB committee) has written an introduction to the Vancouver Benchmarks (<http://interprofessional.ubc.ca/ClaimingFullCitizenship2015/benchmarks.asp>) and has produced a 2-minute video explaining the project (<https://www.youtube.com/watch?v=cvuaJ-PbOdM&feature=youtu.be>). Both Samantha Jenkinson and Leighton Jay are also members of this committee.

The flowchart diagram below identifies the broad areas in which government action might be needed. The Vancouver Benchmarks project is developing more action-oriented statements that will sit behind these boxes and arrows.



Useful Resources

There are many useful resources from the Vancouver Conference that are now publicly available.

A wide range of videos from the Vancouver Conference has been made available publicly at: <http://members.shaw.ca/bsalisbury/index.html>. On this website, these are organised into various categories that include keynote addresses, recommended videos and video interviews with 'experts' on a wide range of citizenship-related topics. These interviews are professionally produced and are typically quite short, creating a rich database of expert opinion on a range of relevant topics.

Some of the keynote speakers you can see and hear on this website include:

Sue Swenson (USA) – her reflections on the Conference (Saturday 17th Oct)

Tom Nerney (USA) – State of the Nations address for the USA (Friday 16th Oct). This is a very practical view of what citizenship looks like for people with high support needs and where quality systems could focus to transform services and one that I personally found very helpful.

Bruce Bonyhady (Chair of the NDIS Board) – a 25-minute overview of the NDIS. This is a clear and lucid explanation of the Scheme and how and why it is being conceived and designed as it is.

Ellen Goodey (England) – compellingly telling her own story of citizenship.

Jim Mann (Canada) – telling his own story of living with Alzheimers Disease and hanging onto his 'citizenship'.

The **Vancouver Conference website** is:

<http://interprofessional.ubc.ca/ClaimingFullCitizenship2015/>

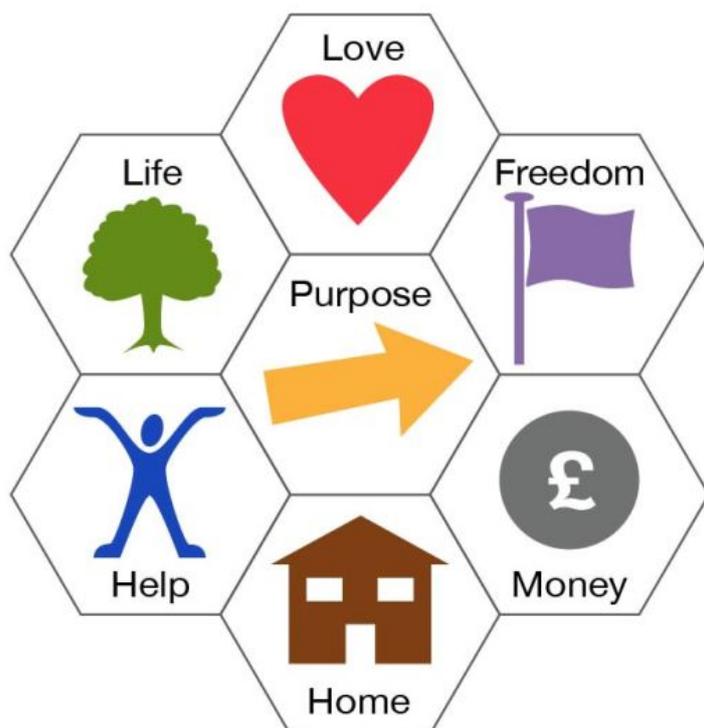
Community Living Essex County (Canada - <http://communitylivingessex.org>) is a service provider in Ontario that has successfully established a structured way of supporting and promoting both family leadership and people with intellectual disability being able to represent themselves effectively. This short video explains the approach they have used: <https://youtu.be/vGGww-1Zo70>.

Inclusion Alberta (Canada - <http://inclusionalberta.org>) has been noted as an organisational 'example of excellence' when it comes to supporting people with disabilities to claim full citizenship.

If you're interested in knowing more about **microboards**, please contact Susan Stanford directly (susan@youniverse.org.au) and check out the local expertise at: <https://www.facebook.com/Microboards-Australia-174827905874603/>. After 25 years establishing microboards in British Columbia, Vela Canada also has numerous microboard resources available through their website (<http://www.velacanada.org>) and Facebook page (<https://www.facebook.com/VelaCanada>).

WA Individualised Services has some excellent **Supported Decision Making** resources available. Written and video resources are free and available online at: <http://waindividualisedservices.org.au/supported-decision-making-project-resources/>.

Keys to Citizenship – Simon Duffy: The Centre for Welfare Reform (UK)



- 1 **Purpose** - we live a life of meaning
 - 2 **Freedom** - we can pursue our purpose
 - 3 **Money** - we have the means to pursue our goals
 - 4 **Home** - we can belong in community, but also protect our privacy
 - 5 **Help** - we can offer others opportunity
 - 6 **Life** - we can contribute in our own way
 - 7 **Love** - we can build relationships and new life
- (<http://simonduffy.blogspot.com.au/2013/11/the-keys-to-citizenship.html>)

Tom Nerney (USA): If we focus supports, services and quality systems on these four things, we will be supporting self-determination and potentially transforming lives.

1. A place to call home where the person has control over the front door and who comes into their home for any reason;
2. Being active in their community including meaningful membership and valued contributions. This includes control over their means of transport to access the community;
3. Establishing and maintaining long-term relationships and friendships including intimate ones; and
4. Addressing 'forced impoverishment' through enabling participation in the workforce and/or a microbusiness.

"The goal is that we will walk and wheel together – as equals; we will dine together – as equals; we will work together – as equals; and we will love each other as equals."

Sue Swenson (USA): "Being the parent or family member of a person with profound disability is a profound experience. It's not that we want our sons and daughters to belong to community. It's that we actually create community by bringing them there. And sometimes, disability drives citizenship in ways that we don't talk about."